



**National
Multiple Sclerosis
Society**

**Multiple Sclerosis Tax Check-off
Program Report**

Reporting Period January 1 – December 31, 2022



The National Multiple Sclerosis Society's New Mission Statement as of November 2020:

We will cure MS while empowering people affected by MS to live their best lives.

BACKGROUND

Multiple sclerosis, an unpredictable, often disabling disease of the central nervous system, interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. The progress, severity, and specific symptoms of MS in any one person cannot yet be predicted, but advances in research and treatment are moving us closer to a world free of MS. Most people with MS are diagnosed between the ages of 20 and 50, with at least two to three times more women than men being diagnosed with the disease. A new study funded by the National MS Society has confirmed that nearly one million people are living with MS in the United States, more than twice the original estimate from a previous study. The Society serves over 550,000 registered people with MS and their families, including more than 13,400 individuals with the disease in Wisconsin.

While we've long understood the financial burden on people with MS and their families, a recent study highlights the far reaching and considerable cost of this disease on the entire U.S. economy and the real impact these costs have on people with MS, their families and care partners. It highlights the urgent need for policymakers and other stakeholders to help lower the cost of care and treatment of MS, a lifelong, chronic disease.

For the nearly 1 million people living with MS in the U.S., the annual economic burden — the cost to all of society, including individuals living with MS, government (federal, state and local), employers, health insurers and more — is \$85.4 billion. Of that \$63.3 billion makes up direct medical costs including medications, healthcare visits and medical equipment; \$21 billion for missed work and/or early retirement; and \$1.1 billion for caregiving and home/vehicle modifications.

In December 2005, Governor Jim Doyle and members of the State Legislature led by a bi-partisan group of legislators, created the 2005 Wisconsin ACT 71 to assist those who live with MS in Wisconsin. This law established a voluntary income tax check-off on Wisconsin State income tax forms for 2006 and beyond to fund health-related programs and services for people with MS in Wisconsin. Individuals filing Wisconsin State tax returns may now choose to allocate a portion of their tax refund, or add to their tax liability, any amount to fund health-related programs and services.

Under the provisions of ACT 71, the amount received through the income tax check-off after administrative expenses are to be disbursed by the National MS Society–Wisconsin Chapter to fund health-related programs and services for people living with MS in Wisconsin. The following disbursements have been distributed to date:

- In September 2007, the National MS Society –Wisconsin Chapter, received its first appropriation of \$82,284.14, from the State of Wisconsin
- In September 2008, the second appropriation was \$85,765.75
- In September 2009, the third appropriation was \$90,147.28
- In September 2010, the fourth appropriation was \$77,709.41
- In September 2011, the fifth appropriation was \$75,294.95
- In September 2012, the sixth appropriation was \$69,988.39
- In September 2013, the seventh appropriation was \$68,955.88
- In September 2014, the eighth appropriation was \$52,315.12

- In September 2015, the ninth appropriation was \$68,426.56
- In September 2016, the tenth appropriation was \$68,455.52
- In September 2017, the eleventh appropriation was \$69,801.81
- In September 2018, the twelfth appropriation was \$66,297.67
- In September 2019, the thirteenth appropriation was \$60,997.08
- In September 2020, the fourteenth appropriation was \$60,732.38
- In September 2021, the fifteenth appropriation was \$85,024.48
- In September 2022, the sixteenth appropriation was \$77,673.33

(All appropriation totals reflect the donation for that year, less State of Wisconsin’s administrative fees.)

As required by Wisconsin ACT 71, this report summarizes for the State Legislature and the Governor the entities that received check-off funds in the 2022 calendar year.

MS Navigator – A Trusted Partner for Personalized Support

No one should face MS alone. Every person affected by MS deserves a lifelong partner and resource through all the decisions along their journey to manage MS and live the life they want. For too many people living with MS, significant challenges and roadblocks prevents them from living their best lives. Disease progression, social systems, and financial and environmental factors can present seemingly insurmountable obstacles to needed support, home care, medical equipment, insurance, and other benefits. We know these issues exist for many people living with MS.

MS Navigators are a compassionate team of partners available to all people affected by MS, free of charge, to help find sustainable solutions to the challenges of MS.

Personalized Support — One Individual, One Family at a Time

- MS Navigators are professionals with experience in social work, counseling, and health support services, with ongoing training specific to the needs of people with MS.
- Support is one-on-one and customized to the individual because every experience with MS is different.
- MS Navigators across the country are connected to one another, in real time, sharing resources and learnings to more effectively solve problems.
- MS Navigators make strategic use of financial assistance when needed to stabilize a person’s situation as they work on long-term options to meet life goals.
- Specialized case management services are available for those without adequate support systems to provide in-person needs assessment and support to achieve goals of independence and safety—so people can live life their way. Difficult circumstances are addressed, including financial hardship, need for home modifications and care coordination, access to community resources such as meal delivery, and other life-changing and life-saving resources.

Help For All People with MS — Where and When They Need Us

- Services are available for all people affected by MS, regardless of their location.
- Connect with an MS Navigator through one’s preferred engagement method, whether it be phone, email or on our website through our live chat function.



“As my MS progressed and I had to leave work, the emotional and financial strain on our lives was devastating. Past-due bills were piling up. I had no health insurance and couldn’t see a neurologist or get medication. We couldn’t even afford new batteries for my scooter. I was extremely isolated. Then I met Dayna, my case manager, through the National MS Society, and my life changed. She negotiated the donation of an accessible van and helped set me up with Medicaid and a neurologist. I’m now on disease-modifying therapy and have home health aides.” - Patti

APPLICATION AND DISBURSEMENT PROCESS

Individuals affected by MS in need of assistance contact the Society through its MS Navigator Program’s toll-free hotline, email, or chat. Staffed by experienced professionals known as MS Navigators who have deep experience in social work, counseling, and constituent-centered advocacy to address complex needs of people with MS, the service connects constituents to pertinent MS information and resource referrals.

Additionally, as MS creates a range of challenges that can result in short-term financial crises and diminished capacity to pay for goods or services to manage the disease, MS Navigators evaluate requests for financial assistance to help economically disadvantaged families. The Society provides assistance for individuals to access MS-related needs ranging from durable medical equipment and respite care services to emergency support to avoid crisis such as eviction or utility disconnection. The MS Navigator team utilizes unified guidelines that outlines covered items for financial assistance and utilizes set giving ranges, however, individual situations can also be reviewed through a special consideration process and review committee that may exceed the assistance cap for a unique situation. To request financial assistance, applicants are required to submit the following: proof of an MS diagnosis; a prescription for the requested item or service (if medical-related need); and a bill, invoice, or price quote or quotes from independent vendors or service providers.

To ensure the most effective use of Society funding and the most long-lasting solutions for individuals affected by MS, MS Navigators assess each unique situation and partner to find a solution that includes not only Society financial assistance, but also helpful connections to other services and resources as well. MS Navigators effectively leverage a combination of Society assistance with other nonprofit community organization resources to enhance the value of Society funds and maximize resources and impact for people with MS.

In 2022, 371 constituents in Wisconsin connected with MS Navigators to receive support through 2,197 unique interactions. Because of Act 71 funds, direct financial assistance was awarded to an additional 58 Wisconsin constituents in the amount of \$57,322.83 by MS Navigators.



DISBURSEMENTS

The information and table provided below summarizes the Wisconsin ACT 71 Fund disbursements from January 1 through December 31, 2022. Constituents receiving direct financial assistance resided in the following counties:

- Brown
- Dane
- Green
- Green Lake
- Jefferson
- Kewaunee
- La Crosse
- Marathon
- Marinette
- Milwaukee
- Outagamie
- Ozaukee
- Racine
- Rock
- Sauk
- Sawyer
- Shawano
- Sheboygan
- Washington
- Waukesha
- Waupaca
- Winnebago

Benefit Type	Awarded Dollar Amount
Air Conditioner	\$3,072.70
Assistive Technology Devices - High Tech	\$2,875.43
Auto Modification	\$9,981.65
Chore Services	\$1,638.92
Cooling Garments	\$929.84
DME Repair	\$3,000.00
Equipment Assistance	\$1,380.44
Exercise/Recreation Therapy Fees or Supplies	\$500.00
Food and Dietary Supplements	\$600.00
Incontinence Supplies	\$1,617.92
Ramp	\$6,159.99
Rehab Evals/Services	\$650.00
Rent Mortgage and Utilities	\$20,581.82
Shower/Tub Bench	\$827.78
Transportation	\$691.89
Walk Aide	\$1,000.00
Walker with Wheels	\$575.00
Wheelchair Manual	\$1,239.45
Total Financial Assistance	\$57,322.83
Salary and benefits for MS Navigators (social workers) who directly assist people in Wisconsin affected by MS and help determine direct financial assistance	\$20,350.50
Total Wisconsin Funds Spent	\$77,673.33

RESTRICTIONS FOR THE MANAGEMENT OF FUNDS

No administrative costs were deducted from these funds. To the extent feasible, all Wisconsin ACT 71 funds contributed are depleted yearly.

CONTACT INFORMATION

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